

The Cystic Fibrosis Affiliate Center of the Hudson Valley

Annual Care Planner

Age: 12-19 years old

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CYSTIC FIBROSIS ANNUAL CARE RECOMMENDATIONS

Year: _____

Name: _____ Date of Birth: _____

Things to do:

- Annual lab work
- Annual oral glucose tolerance test (if applicable)
- DXA scan (if applicable)
- Annual pulmonary function test
- Annual chest X-Ray
- Annual acid fast bacillus (if applicable)
- Sputum cultures (4 per year)
- Annual visit with Nutritionist/Dietitian
- Annual visit with Respiratory Therapist
- Annual screen for depression & anxiety (if applicable)
- Annual visit with Social Worker/Mental Health Coordinator
- Complete the Patient Annual Demographic Form
- 4 spirometer readings per year (in-office or with home spirometer)
- Abdominal Ultrasound if > 3 years old
- Colorectal screen if > 40 years old or otherwise indicate
- Cataract screening (if applicable)

Keep track of your progress below!

Date of Visit	BMI	FEV1	Culture Done

CFF ANNUAL FORM
To be completed by patient/parent
Date: _____ / _____ / _____

YOUR NAME:	
DATE OF BIRTH:	ZIP CODE:
EMAIL ADDRESS:	
INSURANCE:	
What type of Insurance do you have? <input type="checkbox"/> Private <input type="checkbox"/> Medicare <input type="checkbox"/> Medicaid <input type="checkbox"/> State special needs program <input type="checkbox"/> TriCare/Military <input type="checkbox"/> Indian Health Service <input type="checkbox"/> Other: _____ <input type="checkbox"/> No insurance	
Are you under a PARENT'S INSURANCE? <input type="checkbox"/> Yes <input type="checkbox"/> No	
Do you receive ASSISTANCE FROM A PATIENT ASSISTANCE PROGRAM? <input type="checkbox"/> Yes <input type="checkbox"/> No	
DEMOGRAPHICS:	
BIOLOGICAL SEX AT BIRTH: <input type="checkbox"/> Male <input type="checkbox"/> Female	
RACE/ETHNICITY: <input type="checkbox"/> Decline to answer <input type="checkbox"/> White <input type="checkbox"/> Black/African American <input type="checkbox"/> Asian <input type="checkbox"/> American Indian or Alaska Native <input type="checkbox"/> Native Hawaiian or Other Pacific Islander <input type="checkbox"/> Some other race <input type="checkbox"/> Two or more races: select all that apply <input type="checkbox"/> White <input type="checkbox"/> Black/African American <input type="checkbox"/> Asian <input type="checkbox"/> American Indian or Alaska Native <input type="checkbox"/> Native Hawaiian or Other Pacific Islander	
<input type="checkbox"/> Hispanic Origin: <input type="checkbox"/> Yes <input type="checkbox"/> No	
MARITAL STATUS (Age 18 or older): <input type="checkbox"/> Single <input type="checkbox"/> Living together <input type="checkbox"/> Married <input type="checkbox"/> Separated <input type="checkbox"/> Divorced <input type="checkbox"/> Widowed <input type="checkbox"/> Decline to answer	
EMPLOYMENT (Age 18 or older): <input type="checkbox"/> Part Time <input type="checkbox"/> Full Time Homemaker <input type="checkbox"/> Full Time Employment <input type="checkbox"/> Unemployed <input type="checkbox"/> Student <input type="checkbox"/> Disabled <input type="checkbox"/> Retired <input type="checkbox"/> Decline to answer	

EDUCATION LEVEL:PATIENT (You):

less than high school High school Some College College Master Doctorate
 Decline to answer

Patient's Father:

less than high school High school Some College College Master Doctorate
 Decline to answer

Patient's Mother:

less than high school High school Some College College Master Doctorate
 Decline to answer

Patient's Spouse:

less than high school High school Some College College Master Doctorate
 Decline to answer

How many people are in your household, including yourself? _____ Decline to answer

What is your estimated ANNUAL HOUSEHOLD INCOME?

\$ _____ Decline to answer

SMOKING

Did you smoke cigarettes?

No
 Yes, less than 1 pack per day
 Yes, 1 or more pack per day
 decline to answer
 Not applicable

Does anyone in your household smoke cigarettes? Yes No Decline to answer

How often are you exposed to secondhand smoke?

Never
 Daily
 several times per week
 several times per month or less
 declined to answer
 Unknown

VAPING

Did you use electronic cigarettes (vaping)? Yes No Decline to answer

How often did you vape? Everyday Some days Not at all Decline to answer

IMMUNIZATION

Did you receive the influenza vaccine this year? Yes No Decline to answer

Did you receive COVID vaccine? Yes No Decline to answer

PULMONARYDo you use OXYGEN? Yes NoIf YES: Continuous Nocturnal and/or with exertion During exacerbation As neededDo you use any NON-INVASIVE VENT? (assisted breathing, BiPap, CPAP, etc): Yes NoDid you have a CHEST X-RAY this year? Yes No**EYE CARE**Did you get checked for cataracts this year? Yes No Unknown

If you have diabetes, did you have a retinal exam done by an ophthalmologist?

 Yes No Unknown Not applicable**PREGNANCY:** Not applicableAre you or were you PREGNANT this year? Yes No Decline to answer

If YES, date of last LMP: ____ / ____ / ____

If YES, outcome of pregnancy:

 Live stillbirth spontaneous abortion therapeutic abortion undelivered decline to answer

Date of outcome: ____ / ____ / ____

IF AGE 2 YEAR or LESS: Not applicableDid your child attend DAYCARE this year? Yes No UnknownDid your family receive genetic counseling this year? Yes No UnknownWas your child given SYNAGIS this season (Sept - Jan)? Yes No UnknownPlease return completed pediatric patient forms to:

New York Medical College
 Attn: Boston Children's Health Physicians
 Dr. Elizabeth de la Riva-Velasco
 40 Sunshine Cottage Rd
 Skyline 1NE29
 Valhalla, NY10595
 Fax: (914)614-4261

Please return completed adult patient forms to:

Dr. Timothy Collins
 21 Reade Place, suite 1000
 Poughkeepsie, NY 12601

CF Affiliate HVNY 1.26

**Patient Health Questionnaire and General Anxiety Disorder
(PHQ-9 and GAD-7)**

Date _____ Patient Name: _____ Date of Birth: _____

Over the last 2 weeks, how often have you been bothered by any of the following problems? Please circle your answers.

PHQ-9	Not at all	Several days	More than half the days	Nearly every day
1. Little interest or pleasure in doing things.	0	1	2	3
2. Feeling down, depressed, or hopeless.	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much.	0	1	2	3
4. Feeling tired or having little energy.	0	1	2	3
5. Poor appetite or overeating.	0	1	2	3
6. Feeling bad about yourself – or that you are a failure or have let yourself or your family down.	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television.	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed. Or the opposite – being so fidgety or restless that you have been moving around a lot more than usual.	0	1	2	3
9. Thoughts that you would be better off dead, or of hurting <u>yourself in some way</u> .	0	1	2	3
Add the score for each column				

Total Score (add your column scores): _____

If you checked off any problems, how difficult have these made it for you to do your work, take care of things at home, or get along with other people? (Circle one)

Not difficult at all

Somewhat difficult

Very Difficult

Extremely Difficult

Over the last 2 weeks, how often have you been bothered by any of the following problems?

Please circle your answers.

GAD-7	Not at all sure	Several days	Over half the days	Nearly every day
1. Feeling nervous, anxious, or on edge.	0	1	2	3
2. Not being able to stop or control worrying.	0	1	2	3
3. Worrying too much about different things.	0	1	2	3
4. Trouble relaxing.	0	1	2	3
5. Being so restless that it's hard to sit still.	0	1	2	3
6. Becoming easily annoyed or irritable.	0	1	2	3
7. Feeling afraid as if something awful might happen.	0	1	2	3
<i>Add the score for each column</i>				

Total Score (add your column scores): _____

If you checked off any problems, how difficult have these made it for you to do your work, take care of things at home, or get along with other people? (Circle one)

Not difficult at all

Somewhat difficult

Very Difficult

Extremely Difficult

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CF ANNUAL NUTRITION SCREEN
PEDIATRIC (12-19 years old)

Name _____ **Date** _____

TO BE COMPLETED BY PATIENT:

1. Have you had any bone fractures, broken bones, or falls in the past year?

Yes, Explain: _____
 No

2. Have you noticed more than usual bruising in the past year?

Yes, Explain: _____
 No

3. Have you had any of the following changes in bowel function in the last 6 months? Indicate all that apply:

Increase frequency
 Decreased frequency
 Loose stools
 Hard stools
 Abnormal/Foul smelling stool
 Color changes in stool
 Other _____
 None

4. There is not enough food in the home for the entire family

Often true ____ Sometimes true ____ Never True ____

5. It is difficult to afford supplements, vitamins, formula, or tube feeding supplies

Often true ____ Sometimes true ____ Never True ____

6. Which of the following weight trends have you noticed most recently?

Weight gain
 Weight loss
 No weight change
 Other: _____

7. Does your weight affect the way you feel about yourself?

Often ____ Sometimes ____ Never ____

8. Do you worry you have lost control over how much you eat?

Often ____ Sometimes ____ Never ____

9. Which of the following are true for you in the last week?

- Eating more than usual
- Eating less than usual
- Eating the same as usual

10. Which of the following are true for you in the last month?

- Increased energy, activity, or exercise
- Decreased energy, activity, or exercise
- No changes in energy, activity, or exercise

Thank you for completing this survey!

If you have any questions, concerns, or topics you'd like to discuss with your dietitian please list them below or call 845-214-1850 to make an appointment in person or via telehealth!

TRANSITIONING YOUR CARE

The CF Foundation has made tremendous progress in supporting research and development of medications and therapies which has extended the life expectancy of those living with CF. Today, 60% of people living with CF are adults. The CF Affiliate Center of the Hudson Valley provides care for both pediatric and adult patients.

The CF Affiliate Center of the Hudson Valley is committed to provide you with the very best care. Adults living with CF have medical conditions and needs that are best cared for by an adult physician. With this in mind, after your 16th birthday, we are encouraging you to transition your CF care to a CF adult pulmonologist of your choice so that your unique needs will be met. If you decide to stay with our Center, you will still have the same Dietitian and Social Worker/Mental Health Coordinator, however, you will transition to the Respiratory Therapist at the adult center. If you need admission to the hospital you would be admitted to Vassar Brothers Medical Center where the adult pulmonologists care for their patients. There will be a comprehensive hand off between the pediatric and adult physicians so your specific needs will continue to be met.

The first step is to schedule your first appointment with the adult pulmonologist. When you have that date, schedule a final appointment with your pediatric pulmonologist (this should be 2-4 weeks prior to your adult appointment) who will address any current concerns. Then your pediatric physician will call the adult pulmonologist to do the comprehensive handoff and your medical records forwarded. After your first adult physician visit you will be under their care and the transition will be complete.

We understand this is a difficult change but we are here to support you through it. Thank you for trusting us with your care.

All the best,

The CF Affiliate Team

Cystic Fibrosis and the Liver

Liver and Spleen Ultrasound Screening

The liver is one of the vital organs of the body. It has over 500 functions that keep the body working properly. These liver functions include:

- Making bile which helps break down fats during digestion. The bile is stored in the gallbladder.
- Converting excess blood sugar (glucose) into glycogen for storage to be used as needed, helping to keep blood sugar balanced.
- Regulating blood levels of amino acids, which are the building blocks of proteins.
- Regulating blood clotting to prevent abnormal bleeding or clotting.
- Processing hemoglobin in red blood cells for its iron content (the liver stores iron).
- Clearing bilirubin from processed red blood cells. Bilirubin build-up turns the skin and eyes yellow.
- Making immune factors to fight infection and removing bacteria from the bloodstream.



People with cystic fibrosis may develop liver problems that keep the liver from performing its many functions properly. For example, in people with cystic fibrosis, the bile can become so thick that it makes gallstones. CF can also cause the liver to become stiff and raises the blood pressure within the liver and the spleen.

The best ways to detect any changes to liver health are:

- Regular doctors visits for physical exams.
- Blood tests to screen for any changes in liver functions.
- Ultrasound to screen for any changes in the liver, gallbladder and spleen.

The ultrasound of liver, gallbladder and spleen does not involve any radiation and does not require any special preparation. The Cystic Fibrosis Foundation recommends a screening ultrasound of the liver, gallbladder and spleen every 2 years for children from age 3 to 18 years. Adults with CF should have at least one baseline screening ultrasound.

A prescription for screening ultrasound of liver, gallbladder and spleen will be provided by your CF doctor. The ultrasound can be scheduled at any of the following imaging facilities:

Vassar Brothers Medical Center	Scheduling: 845-790-8855
WMC-Mid-Hudson Regional	Scheduling: 845-431-8776
WMC-Valhalla Advanced Imaging Center	Scheduling: 914-493-2500
MD Imaging	Scheduling: 845-471-2848

For additional information on CF associated liver disease, speak with your CF physician or visit CFF.org.

Cystic Fibrosis (CF) and Bone Health

How Does CF Affect the Health of Your Bones?

Since people with CF can have low bone minerals, they are at risk for osteopenia and osteoporosis. In CF, it can happen at any age but becomes more common in the later teen and adult years. This causes brittle bones and can lead to pathologic bone fractures.

Osteopenia: Bones do not have enough minerals



Normal bone



Osteoporosis

Osteoporosis: Holes in the bones are too big

Pathologic Bone Fractures: A break in the bone that was not caused by force or impact.

Contributing Factors to Bone Disease:

- Low BMI or weight
- Pancreatic insufficiency
- Calcium, Vitamins D, or Vitamin K deficiencies
- Lung infections and low FEV1
- Steroid use
- Physical inactivity
- Advancing age
- History of fracture(s)
- Delayed onset of puberty

How to Keep Your Bones Healthy:

Maintain healthy BMI & weight	Maintain normal calcium, vitamin D, and vitamin K levels	Incorporate weight bearing exercises
Follow up with your registered dietitian annually	Complete routine lab work and recommended DEXA scans (bone density scans)	Complete quarterly physician visits

What is a DEXA Scan?

DEXA (or DXA) stands for Dual-Energy X-Ray Absorptiometry. This radiology test uses a small amount of x-ray to look at the mass and density of bones.



Why Do I Need a DEXA Scan?

DEXA scans are used for screening purposes to evaluate your bone health and bone density. For people with CF, it is recommended that they have an initial scan at age 18, unless otherwise recommended by their physician.

How Long Does the Scan Take?

20 minutes.

Do I have to Prepare for the Test?

No. There is no preparation needed.

Where can I get the Scan?

Vassar Brothers Medical Center

Scheduling: 845-790-8855

WMC-Mid-Hudson Regional

Scheduling: 845-431-8776

WMC-Valhalla Advanced Imaging Center

Scheduling: 914-493-2500

MD Imaging

Scheduling: 845-471-2848

What Happens with My DEXA Scan Result?

Your CF physician or dietitian will review results with you and provide follow up recommendations and/or interventions.

CFTR Modulators and the Eyes

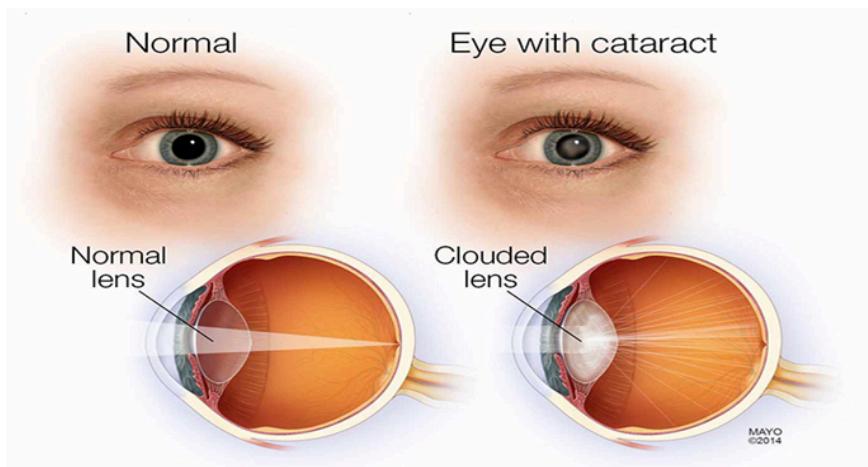
What are CFTR Modulators?

Cystic fibrosis transmembrane conductance regulator (CFTR) modulators are medications designed to correct the malfunctioning protein made by the mutated CFTR gene. Because cystic fibrosis (CF) can be caused by many different CFTR mutations, there are currently five CFTR modulators for people with certain mutations:

- Alfytrek (vanzacaftor/tezacaftor/deutivacaftor)
- Trikafta (elexacaftor/tezacaftor/ivacaftor)
- Symdeko (tezacaftor/ivacaftor)
- Orkambi (lumacaftor/ivacaftor)
- Kalydeco (ivacaftor)

What are Cataracts and What are the Symptoms?

Cataracts are a clouding of the lens of the eye, which is normally clear. This can make it more difficult to see over time. Some symptoms include sensitivity to bright lights, having difficulty seeing at night, blurry vision, double vision, seeing bright colors as faded or yellowed.



How can CFTR Modulators affect Cataracts?

Most cataracts develop due to aging, but CFTR modulators can also cause cataracts. The exact way of how CFTR modulators cause cataracts is unknown at this time. Studies have shown that a small percentage of patients on ivacaftor can develop cataracts within a few years of starting treatment. This is known as ivacaftor-associated or ivacaftor-induced cataracts. As more patients get on modulator treatments, the association between modulators and cataracts will become more clear.

How are Cataracts Diagnosed?

Cataracts are diagnosed with a comprehensive eye exam that looks for any abnormalities to the lens and other parts of the eyes.

I am on a CFTR Modulator. When should I get checked for Cataracts?

Ideally, an exam to screen for cataracts should be done prior to starting CFTR modulator therapy. Once on a CFTR modulator, a yearly eye exam is recommended. Talk to your CF physician about getting a referral to an ophthalmologist (a medical doctor who specializes in care and treatment of the eyes) if you are already on a CFTR modulator and have not had an eye exam, or if you are eligible for a CFTR modulator and are considering starting treatment.

References

[CFTR Modulator Therapies | Cystic Fibrosis Foundation](#)

[What Are Cataracts? - American Academy of Ophthalmology](#)

[Ivacaftor-induced Cataracts in Patients with Cystic Fibrosis - EyeWiki](#)

Schools guide to Cystic Fibrosis

About Cystic Fibrosis

CF is a life-threatening genetic disease. It is **not** contagious and does not affect cognitive ability.

In people with CF, a defective gene causes the body to produce unusually thick, sticky mucus that can clog the lungs, pancreas and other organs. This buildup can lead to severe respiratory and digestive problems that may warrant special accommodations in a school setting.

CF affects each person differently. Some people with CF are in good general health, while others are severely limited by the disease and are unable to attend school regularly. It is important that you meet with your student's parents and CF health care providers to determine the best way to support your student's unique needs.

CF and Nutrition

In people with CF, mucus can obstruct the digestive system and prevent proper absorption of nutrients, which can slow growth.

To boost growth and nutrition, children with CF take pancreatic enzymes and vitamins. Some children with CF may follow a special diet.

Meet with your student and his or her parents about ways to help your student maintain a healthy diet. Examples of accommodations may include allowing the child with CF more time to eat during lunch, to snack throughout the school day, to carry a water bottle, and to take enzymes with each snack and meal.

Although enzymes help with digestion people with CF may still experience abdominal pain, foul-smelling gas, or diarrhea. This is why it is important to:

- Give a student with CF frequent access to the bathroom.
- Not draw attention to the student if she or he passes gas frequently.
- Make the student feel comfortable about going to the bathroom when needed.

Exercise

Although some people with CF have difficulty breathing and may tire easily, regular exercise is generally encouraged because it helps loosen the mucus that clogs the lungs and strengthen the muscles used to breathe. Exercise also promotes healthy social interaction with peers.

To help determine the appropriate level of physical activity for your student:

-Talk to the student and parents about the activities they are comfortable with.

-Include the student in all games and activities in which he or she is interested.

Dehydration is a real concern for people with CF who are active because they can lose more salt when they sweat than those who do not have CF. During exercise, encourage your student to:

-Drink 6 to 12 ounces of fluid every 20 to 30 minutes.

-Consider sports drinks with added carbohydrates and salt.

-Avoid drinks with caffeine, which can increase fluid loss.

Coughing

People with CF tend to cough a lot to clear mucus from their lungs. In a classroom, a student with CF may feel self-conscious about coughing in front of others. You can help your student feel more comfortable by:

-Making it easy for the student to drink water at his or her desk or slip out of the classroom for water.

-Not drawing attention to the student who is coughing.

-Encouraging your student to keep a box of tissues to cough into and a trashcan to dispose of the tissue near their desk.

-Allowing the student to clean his or her hands with alcohol-based hand gel at their desk.

Infection Prevention and Control

The thick mucus that builds up in the lungs of people with CF allows germs to thrive and can lead to serious lung infections. As a result, people with CF are more vulnerable to getting sick by catching germs from others who are sick, and particularly from others with CF.

The Cystic Fibrosis Foundation's Infection Prevention and Control Guidelines help people with CF, their families, and caregivers reduce the spread of germs in everyday life, including school settings, and provide the following recommendations:

-Keep a minimum 6-foot distance (2 meters) from others with a cold, flu, or an infection in all settings, especially indoors

-Encourage everyone to wash their hands by making soap and water or alcohol-based hand gel readily available in the classroom. Cleaning hands is particularly encouraged after using commonly shared items (such as pencil sharpeners or lab equipment).

-Avoid sharing personal items, such as straws or eating utensils.

-Encourage students to cover their cough or sneeze with a tissue. Throw the tissue away immediately, then wash or clean hands. If a tissue is not available, encourage students to cough or sneeze into their inner elbow.

While lung infections in people with CF pose no danger to the public, they do pose a significant danger to others with CF. If there is **more than one person with CF at your school** (unless they are siblings from the same household), it is **essential** that they keep a safe distance from each other. People with CF should maintain at least a 6-foot distance from each other. They should not sit near each other in class or on a school bus. They should never share water bottles or other personal items.

For additional readings and an informational video on germs, infection control and how students with Cystic Fibrosis can be protected through everyday action and precautions. You may also visit the Cystic Fibrosis Foundation website, or contact Boston Children's Health Physicians to speak with our physicians or staff members.

Help For Your Students and Their Families

Living with cystic fibrosis demands complex care and treatment, which involves navigating a maze of health concerns. Families and students with cystic fibrosis have to go to the doctor multiple times a year for routine follow up, in addition may need lab work, tests and treatments. This may cause the student to miss school, need additional time with assignments and miss some activities. Please refer to the students 504 or IEP plan and reach out to our office for any additional questions or concerns.

Appointment Directory

Laboratory Services:

- Vassar Diagnostics (845)790-8855 45 Reade Pl., Poughkeepsie, NY 12601
- WMC - MHRH Lab (845)483-5917 1 Webster Ave., Suite 204, Poughkeepsie, NY 12601

Diagnostic Imaging Centers:

- Vassar Brothers Medical Center (845)790-8855 45 Reade Pl., Poughkeepsie, NY 12601
- WMC - MHRH Radiology (845)431-8776 241 North Rd., Poughkeepsie, NY 12601

Social Worker & Mental Health Coordinator Appointments (Telehealth available)

- Addison Forgit (914)504-0162 19 Bradhurst Ave, Hawthorne, NY 10532
- Caitlin Lennon (914)504-0166 19 Bradhurst Ave, Hawthorne, NY 10532

Respiratory Appointments (Telehealth available)

- Claudia Salazar, BSRT, RRT-ACCS
 - Telehealth: Email claudia.salazar@nuvancehealth.org
 - In-Person: Vassar Brothers Medical Center, 45 Reade Pl., Poughkeepsie, NY 12601
 - (845)790-8855 Central Scheduling

Dietitian Appointments (Telehealth available)

- Michelle Triolo 845-437-3026 45 Reade Pl., Poughkeepsie, NY 12601
- Lauren Jackson 845-214-1850 Vassar Brothers Medical Center
21 Reade Pl., Poughkeepsie, NY 12601

Pulmonary Function Tests

- Vassar Diagnostics (845)790-8855 45 Reade Pl., Poughkeepsie, NY 12601
- Westchester (914)493-5491 19 Bradhurst Ave, Hawthorne, NY 10532
- Middletown (845)281-7657 212 Crystal Run Rd, Middletown, NY 10940